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Native American and Hispanic Women with Breast Cancer

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| <p>Purpose: The aim of this study was to describe the factors associated with delays in breast cancer treatment among New Mexico Hispanic, Native American and non-Hispanic white women.</p> <p>Scope: The study is currently enrolling a total of 70 participants, 35 patients and 35 caregivers identified by the patient. This ethnographic study will gather data on the psychosocial, cultural, attitudinal, spiritual and demographic variables associated with delays and refusals in breast cancer treatment. The focus of the semi-structured interview is to encourage the women in story-telling about their breast cancer experiences. Interviews will be conducted for a minimum of two sessions. The study has received input from regional community health advisors, breast cancer survivors, The Gathering of Cancer Support, and People Living Through Cancer. Other organizations supporting the study include; the New Mexico Breast and Cervical Cancer Detection and Control (B&CC) Program, the Mexico Tumor Registry, the Health Promotion and Disease Prevention Programs (HPDP) at the Gallup Indian Medical Center, the Northern Navajo Medical Center in Shiprock, and the Crownpoint Healthcare Facility.</p> <p>Summary: Accomplishments for this project period include; 1) Finalization of study selection resulting in forty-six eligible cases 2) Data tables are presented and summarized on forty-six cases based on document reviews conducted by the investigator, by treatment –delays & refusals, ethnicity, and age. 3) Investigator is currently completing data collection of patient interview (second phase) drawn from the forty-six eligible cases 4) Poster presentations on preliminary data from the study at -1) "Era of Hope" Department of Defense Annual Breast Cancer Conference June 7-11 2000 -2) Association for the Behavioral Sciences and Medical Education Annual Meeting in Santa Fe, October 12-15, 2000- "Integrating Culture and Complementary Medicine: Challenges to the Biomedical Model" 5) The investigator completed doctoral comprehensive examination requirement (March of 2000) and is now a Doctoral Candidate.</p> | | | |
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5. INTRODUCTION

Scope of the Research

Little is known about patient perceptions in the management of breast cancer among New Mexico women with breast cancer. Data from the New Mexico Tumor Registry indicates that despite lower incidence of the disease among Hispanic and Native American populations, for those women diagnosed with the disease the prognosis of survival is worse, even when adjusted for stage ^{1,2}. Current breast cancer research focusing on these populations has been primarily epidemiological in nature. Other research suggests that acknowledgment of the cultural influences on patients' treatment decisions, including traditional health practices, is necessary to optimize the benefits of the patient-provider partnership ^{3,4,5}.

Qualitative methods have been successfully used to examine the experiences of women treated for breast cancer ^{6,7,8}. The data collection techniques in qualitative studies (in-depth interviewing, focus groups) allow for the patient to tell her story in her own words. Qualitative methods have also been recommended by researchers in the field as a method that allows women of diverse ethnic backgrounds to share their stories in a nonjudgmental way.

This qualitative study has been conducted in two phases. The first phase involved an informal data gathering process which included consultations with community members and document reviews of cases identified through the Breast and Cervical Cancer and Detection (B&CC) Program in New Mexico. Breast cancer cases were identified of women who had delayed or refused at least one treatment modality. Data are presented for this first phase of the study in this report. Data on forty-six document reviews conducted by the investigator on the treatment delays, refusals, ethnicity, and age identified are presented in this report. The second phase involves an ethnographic

qualitative design that includes comprehensive in-depth interviews with women who have refused or delayed treatment for breast cancer. Interviews are also being conducted with a family member in order to learn more about the experiences and the impact of breast cancer on the family. It is the second phase of this study that the investigator is currently completing as part of the requirements for the doctorate.

6. BODY

Annual Summary

Finalization of Study Cases

In the previous annual summary we reported the study's enrollment goal of thirty-five Native American, Hispanic and Non-Hispanic white women diagnosed with breast cancer and thirty-five identified family members/caregivers. Cases were identified through the breast cancer database of the Breast and Cervical Cancer (B&CC) Program. In the 1997-1998 annual summary we reported that the records of 371 patients referred for their recommended first course treatment (surgery, chemotherapy, radiation, hormonal and immunotherapy) and identified in the B&CC Program and New Mexico Tumor Registry (NMTR) database were reviewed. This review yielded a total of thirty-five participants who met the study's inclusion criteria. This list of thirty-five potential participants was then reviewed and cross-checked to obtain patient status (living or deceased) and follow-up physician. In the last reporting period an additional 178 cases were identified, (matched file with the NMTR, December 1998). This review was completed yielding an additional 11 cases. The study identified and finalized the identification of forty-six eligible cases for review.

Selection of Cases

As presented in the previous annual report all B&CC Program breast cancer cases underwent a "match" with the New Mexico Tumor Registry. The method employed to identify eligible cases involved identifying cases who's record indicated a SEER code of "7" (patient or patient's guardian refused the specific therapy) or "8" (treatment recommended, unknown if administered). These cases were selected and included in the study. In the case of surgery, cases that had a code of "10" (indicates the patient had less than a total mastectomy and or just an excisional biopsy) or a code of "00" (no surgical

procedure) were also selected and included. Based on this review process and the study criteria, forty-six cases were selected for the study.

Document Reviews of Cases

The investigator closely reviewed the records of forty-six breast cancer patients diagnosed and treated in New Mexico. Patient characteristics, such as ethnicity and age are presented in this report (Tables 1&2). Furthermore, an extensive review of the information provided in these records (narratives from physicians & nurses, SEER data collected by the abstractors) led to five investigator-created categories reflecting the treatment patterns of the women in this study (Tables 3-7). The group data presented in these tables (from document reviews) tell us whether treatment took place. However, we don't know the reasons for the treatment patterns (delay, refusals, and no shows) among this group of underserved women with breast cancer. The investigator's current collection of data (patient interviews) and analysis, will tell us more about this.

Summary and Discussions from Document Reviews

Data on forty-six document reviews conducted by the investigator on treatment delays, refusals, ethnicity, and age are presented in this report. Each table will be summarized.

Table 1.
Participant Age
(N= 46)

| Age at Diagnosis | Percent |
|-------------------------|----------------|
| 40-49 (12) | 26 |
| 50-64 (24) | 52 |
| 65 and older (10) | 22 |
| 46 | 100 % |

Table 1. Fifty-two percent of the women in the study are between the ages of 50-64.

Table 2.
Participant Ethnicity
(N= 46)

| Ethnicity | Percent |
|---------------------------|------------|
| Non-Hispanic White (8) | 17 |
| Hispanic (14) | 31 |
| Native American (24) | 52 |
| 46 | 100 |

Table 2. Fifty-two percent of the cases identified in the study are of Native American descent, 30 percent Hispanic and 17 percent Non-Hispanic White.

Table 3.
Unknown if Treatment Recommended was Completed
(N= 46)

| Ethnicity | Treatment | # Cases |
|---------------------------|--------------|---------|
| Non-Hispanic White (8) | Hormonal | 3 |
| | Chemotherapy | 2 |
| Hispanic (14) | Radiation | 2 |
| | Chemotherapy | 1 |
| Native American (24) | Hormonal | 1 |

Table 3. Depicts the number of times there was an entry for the category "Unknown" (the SEER code "8" for breast cancer) by ethnicity and specific treatment modality. These cases will require periodic review in order to determine if the treatment was eventually completed, refused or lost to follow-up.

Table 4.
Treatment Refused
(N= 46)

| Ethnicity | Treatment | # Cases |
|---------------------------|--------------|---------|
| Non-Hispanic White (8) | Chemotherapy | 2 |
| Hispanic (14) | Mastectomy | 3 |
| | Chemotherapy | 5 |
| | Radiation | 2 |
| | Hormonal | 3 |
| Native American (24) | Mastectomy | 5 |
| | Chemotherapy | 4 |
| | Radiation | 3 |
| | *LND | 1 |
| | Hormonal | 1 |

* Lymph node dissection

Table 4. Depicts the number of times there was an entry for the category "Treatment Refused by Patient" (a SEER code "7" for breast cancer) by ethnicity and specific treatment modality. It is interesting to note the similarity in the type of treatment refused for both Native American and Hispanic.

Table 5.
Treatment Delayed
(N= 46)

| Ethnicity | Treatment | # Cases |
|---------------------------|------------------|----------------|
| Non-Hispanic White (8) | LND | 1 |
| Hispanic (14) | Mastectomy | 3 |
| Native American (24) | Mastectomy | 5 |

Table 5. Depicts the number of times the treatment was “Delayed” (the investigator created and defines this periods as: a recorded entry showing that a specific treatment was recommended but patient initially refused it only to have it completed later (range 3 months to 2 years). Several notations in the record show attempts made by either the nurse or physician to get the patient to return. In some cases, notations are made at disease progression upon return by the patient from the earlier diagnosis. This is evident in the extensive amount of treatment recommended for the patient upon her return.

It is interesting to note that mastectomy was the type of treatment most often delayed for both Hispanic and Native American women.

Table 6.
Treatment Discontinued
(N= 46)

| Ethnicity | Treatment | # Cases |
|---------------------------|------------------|----------------|
| Non-Hispanic White (8) | Chemotherapy | 1 |
| Hispanic (14) | 0 | 0 |
| Native American (24) | 0 | 0 |

Table 6. Depicts the number of times the treatment was “Discontinued” (the investigator created and defines this category as: a recorded entry showing that a specific treatment was initiated but was discontinued at the patient’s request. As noted there was only one case of this type.

Table 7.
Scheduled Treatment Visit Resulted in a
No Show/Lost to Follow-up
(N= 46)

| Ethnicity | Treatment | # Cases |
|---------------------------|------------------|----------------|
| Non-Hispanic White (8) | 0 | 0 |
| Hispanic (14) | 0 | 0 |
| Native American (24) | Mastectomy | 7 |

Table 7. Depicts the number of times the treatment was “Scheduled but Lost to Follow-up” (the investigator created and defines this category as: a recorded entry showing that a specific treatment was scheduled but the patient did not show or cancelled. No other information was provided indicating that treatment was either completed, refused or rescheduled. It is interesting that this category or pattern in treatment was only reflected among the Native American women. Again, the consistent trend of mastectomy being the type of treatment most delayed (both Native American and Hispanic women), and most refused (mostly for Native American) is seen here.

6. KEY RESEARCH ACCOMPLISHMENTS

- The data presented in tables 3-7 does not infer a statistical significance since they primarily describe. However, they are important in revealing a story about these patient's experience with their treatment.
- These reviews do not furnish us with the reasons (fear of treatment effects, body image, barriers to treatment, folk/cultural belief, lack of understanding of the recommended treatment) for these patterns (delays, refusals) in the treatment care of these women.
- It is interesting to note that mastectomy and chemotherapy were the most reported in the refusals, delay and no/show categories for primarily Native American women and Hispanic.
- The investigator feels that the treatment patterns described in this help to further strengthen the significance of the importance of the patient interviews.
- The investigator hopes to glean a more telling story of the experience of breast cancer treatment for these underserved and underinsured ethnic women n New Mexico.

Current Data Collection- Patient Interview

The investigator is conducting data collection (patient & family interviews) with plans to have all data completed in December2000 (see Appendix A for interview guides, contact forms, post cards and study brochure).

7. REPORTABLE OUTCOMES

1) Key Research Accomplishments:

Completion of document reviews, preliminary analysis of descriptive data (age, ethnicity, treatment characteristics) on forty-six study cases.

2) Reportable Outcomes:

- Poster Presentation on Preliminary Data from the study:
 - "Era of Hope" Department of Defense Annual Breast Cancer Conference
June 7-11 2000
 - Association for the Behavioral Sciences and Medical Education Annual Meeting
in Santa Fe, October 12-15, 2000- "Integrating Culture and Complementary
Medicine: Challenges to the Biomedical Model"
- 2) Other reportable outcomes will be reflected in the study's final report (August 2001).
In that final reporting the investigator will report manuscripts submitted or published
findings in peer review journals, abstracts and presentation to scientific conferences,
funding, research opportunities and degrees obtained as a result of this award.
- 3) Copies of cited manuscripts and abstracts will be attached in the final reporting of this
award August 2001.

8. CONCLUSIONS

The investigator recently completed doctoral requirements (written and oral comprehensive examinations) which had some impact on the project timeline. Remaining tasks from the Year 03 Statement of Work include completion of data collection, transcription of interviews, and analysis. Data is being collected and expected to be completed in next 3 months (September-December). The analysis and write-up of data (January through March) will take place in the remaining part of 2001. The investigator's dissertation defense and obtainment doctoral degree is planned for May of 2001 (Fall of 2001 at the latest). In July 2000, a no-cost extension was submitted and approved with an end date of August 31st 2001.

9. REFERENCES

- F. Frost, F. D. Gilliland, K. Tollestrup, C. R Key, C. E. Urbina, *Cancer Epidemiol Biomarkers Prev* 5, 861 (1996).
- F. D. Gilliland, W.C. Hunt, C. Key, *Cancer* 82, 9, 1769 (1998).

3. R Maduro,. December).. *The Western Journal of Medicine* 139, 868-874. (1983,

4. J. W. Molina, *J for Minor Med Students*. 28 (1997).

5. F. Hodge, L. Fredericks, C. Gonzales, *Center for American Indian Research and Education*, Berkeley, CA, (1996).

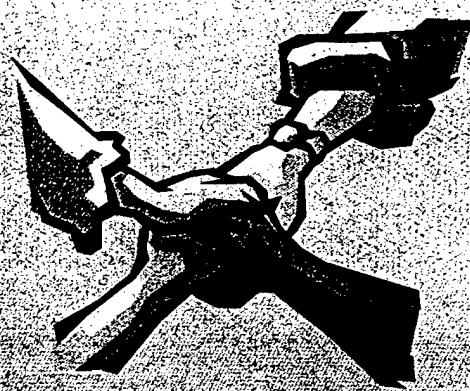
6. B. J. Loveys, & K. Klaich, *Oncology Nursing Forum*, 18,1, 75-80. 1991.

7. F. W Dunaway, W. J., Huestor, & L. Clevinger,. *Journal of the Kentucky Medical Association* 93, 241-245. 1995.

8. B. A Hilton, *Western Journal of Nursing Research*, 16, 366-391, 1994

10. APPENDICES

The
“Sharing
Of Our
Experiences with
Breast Cancer”
Project



Participant Family
Brochure

The
“Sharing
Of Our
Experiences with
Breast Cancer”
Project



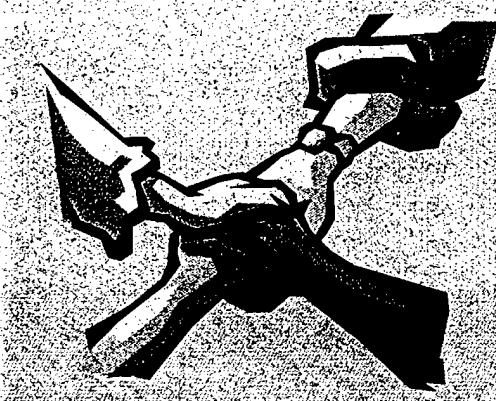
Participant Brochure

El Proyecto
"Hablando
de
Nuestras
Experiencias
con el Cáncer
del Seno"



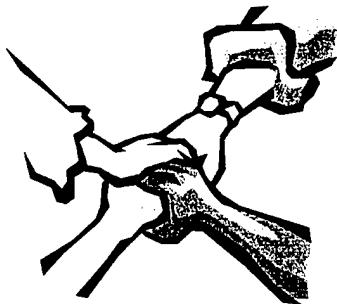
Folleto para la
Participante

El Proyecto
"Hablando
de
Nuestras
Experiencias
con el Cáncer
del Seno"

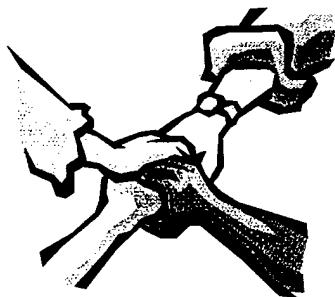


Folleto Para la Familia
del Participante

El Proyecto "Hablando de
Nuestras Experiencias con el
Cancer del Seno"



The "Sharing Of
Our Experiences
with Breast Cancer" Project



The “Sharing of Our Experiences with Breast Cancer” Project Participant Contact Log

| | | | | |
|----------------|-----------|---------|--------|----------------|
| PARTICIPANT ID | 01 | PATIENT | SOURCE | INTERVIEWER ID |
|----------------|-----------|---------|--------|----------------|

M/C= mailed contact letter

I/P= in person contact

T/C= telephone contact

T/LB= telephoned/line busy

T/EB= telephoned/no busy

T/LMF = telephoned/left message w/person
T/LMM = telephoned/left message on machine

T/S= telephone screener completed

A/C= address changed

F/F= face to face interview completed

T/I= telephone interview completed

U/C= unable to complete (deceased, distressed, ineligible)

R≡ refused

LTF= lost to follow-up

PATIENT INTERVIEW GUIDE COVER

**The “Sharing of Our Experiences with Breast Cancer”
(SOEBC) Project**

Case I.D.: **01** **PARTICIPANTID** **PATIENT** **SOURCE** **INTERVIEWERID**

Date of Interview: / /

Language (s) of Interview (please circle one):

English **Spanish** **Spanish & English** **Navajo** **Navajo & English**

SOURCE ID: B&CC - 01, UNMH- 02, PRESBYTERIAN - 03, INDIAN HEALTH SERVICES- 04, LOVELACE-05

Participant Discussion Guide

SECTION III: PRE-DIAGNOSIS AND DIAGNOSIS

First, I would like you to think back around the time before your breast cancer diagnosis. Thinking back to that time tell me...(BEGIN WITH QUESTION 1.)

1. How did you first notice that something had changed with your breasts?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ☛ Can you tell me if you noticed or felt any changes in your breast or felt symptoms before you were diagnosed?
- ☛ Did you find out about it from a screening mammogram or a breast exam?

2. Tell me how you learned about your breast cancer diagnosis?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ☛ Was anyone with you when you were told of your diagnosis?
- ☛ Why did you feel that cancer happened to you?
- ☛ Who informed you of your test results?
- ☛ How were you told?

3. Tell me what you felt when you first heard the word “cancer”?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ➡ Why did you think cancer happen to you?
- ➡ Do you feel you did something to bring on your cancer ?
- ➡ Do you think that you will get well ?
- ➡ Do you think there are things we can do so that we don't get cancer?

4. Tell me how your family learned about your diagnosis?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ➡ Did you talk to anyone in your family about the diagnosis?
- ➡ Who did you tell?
- ➡ How did your family feel when they learned about your diagnosis?
- ➡ Did they feel that you had done something to bring on your cancer?

5. Tell me what was told to you about your treatment for your breast cancer?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ➡ Did a family or friend go with you at this time?
- ➡ How did you feel about what you were told?
- ➡ Did you think that the treatment would remove the cancer?
- ➡ Were you worried about how you would pay for your treatment?
- ➡ Were you worried about whether your body was strong enough to handle the treatment?
- ➡ When did you decide to go in for your first treatment?
- ➡ Was it longer than you wanted to wait? Why was this?
- ➡ Were you given one treatment plan or were you informed about others?
- ➡ Did you go to another doctor or someone else that you trusted for another opinion?

6. Tell me how your family felt about what was told to you about the treatment?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ☛ What did your family think of the treatment plan?
- ☛ Did they think you should get a second opinion?
- ☛ Was your family worried about how you would pay for your treatment?
- ☛ What kind of support or help from family was most important to you? (shopping/baby-sitting/preparing food/household chores)
- ☛ Did you talk to someone in your family who had received treatment for cancer? Who?
- ☛ Who of your family was especially helpful to you?
- ☛ What did they do that was so helpful?

7. Were you given any information about your breast cancer treatment during this time?

- ☛ Did someone give you information about the treatment plan?
- ☛ Did you get information in your own language?
- ☛ Did you read something on the type of treatments planned?
- ☛ Did you talk to anyone in your community that you trust about the treatment planned?
- ☛ Were you told about cancer support groups?

SECTION IV: EXPERIENCES WITH SPECIFIC TREATMENTS

Now, I would like to ask you about the experiences you had with each treatment planned to you by your doctor. Let's begin with your surgery.

8. What was your experience with your surgery for your treatment?**IF PATIENT SAYS SURGERY WAS PLANNED BUT DID NOT COMPLETE PROBE:**

- ☛ What happened that you did not have the surgery as planned?
- ☛ What hospital was your surgery scheduled at? Is this far from your home? How many miles?
- ☛ Did your physician or anyone from the hospital contact you regarding your decision not to have surgery?
- ☛ Did you see someone else that helped you feel better about getting your surgery? Who?
- ☛ Did you decide to have a cleansing or healing ceremony before deciding on surgery?
- ☛ Is there something about the surgery and what it does to you that made you decide not to have it?
- ☛ Is there anything that would have helped you get your surgery for your breast cancer?
- ☛ Did you go back and have it done?
- ☛ Was it far from your home? How many miles is it from your home?
- ☛ Was it hard to get transportation to the hospital?
- ☛ Was it hard to get someone to care for your loved ones?
- ☛ Was it difficult getting your treatment covered under your insurance or any other type of payment plan?
- ☛ Was it hard to get health coverage for this treatment?

If PT. HAD THE SURGERY, PROBE:

- ☛ What type of surgery did you have done?
- ☛ How long after you were told to get your surgery did you get it done?
- ☛ Did you have a cleansing or healing ceremony to help prepare you for your surgery?
- ☛ How did the medical staff accept this preparation?
- ☛ Did you experience difficulties (transportation, second thoughts about the procedure, insurance) in getting the surgery done?
- ☛ Did they speak with you about breast reconstruction?
- ☛ Did the clinic staff or anyone else explain how you would feel after the surgery?
- ☛ Did anyone explain how you would feel once the lymph nodes were removed? Was it explained in your language? Did you get Post-Op instructions on this?
- ☛ Did anyone explain the care you would need after you were discharged for your surgery? Was it explained in your language?

- ➡ Did you have prescribed medications, such as pain medicine, when you were discharged from the hospital?
- ➡ Did you receive instructions for the medicine in a way that you understood about its side effects?

Now, let's talk about other treatments planned for your breast cancer.

9. Was chemotherapy planned as part of your treatment?

IF PATIENT SAYS NO THE CHEMOTHERAPY WAS NOT PLANNED CONTINUE TO RADIATION:

IF PATIENT SAYS IT WAS PLANNED BUT DID NOT GET IT DONE, PROBE:

- ➡ What happened that you did not have the chemotherapy?
- ➡ What hospital was your chemotherapy scheduled at? Is this far from your home?
How many miles?
- ➡ Did your physician or anyone from the hospital contact you regarding your decision not to have your chemotherapy?
- ➡ Did you see someone else for your treatment?
- ➡ Is there anything that would have helped you get your chemotherapy?
- ➡ Was it difficult to get health coverage for this treatment?
- ➡ Were you scared of how the treatment would affect you?
- ➡ Did you need to care for loved ones?

IF PATIENT SAYS YES PLANNED AND DID GET IT, THEN PROBE:

- ➡ How long were you going for chemotherapy treatment?
- ➡ Were there times when it was difficult for you to keep your appointments? Why?
- ➡ Was it difficult getting your treatment covered under your insurance or any other type of payment plan?

- ➡ What hospital was your chemotherapy scheduled at? Is this far from your home? How many miles?
- ➡ Did you see someone else that helped you with the side effects of your chemotherapy?
- ➡ Did you understand which medicine was for your treatment and which was for pain?

10. Was radiation planned as part of your treatment?

IF PATIENT SAYS NO RADIATION WAS NOT PLANNED CONTINUE TO HORMONAL:

IF PATIENT SAYS IT WAS PLANNED BUT DID NOT GET IT DONE, PROBE:

- ➡ What happened that you did not have the radiation?
- ➡ What hospital was your radiation scheduled at? Is this far from your home?
How many miles?
- ➡ Did your physician or anyone from the hospital contact you regarding your decision not to have your radiation?
- ➡ Did you see someone else for your treatment?
- ➡ Is there anything that would have helped you get your radiation for your breast cancer?
- ➡ Was it difficult to get health coverage for this treatment?
- ➡ Were you afraid of how the radiation would affect your body?
- ➡ Did you need to care for your loved ones?

IF PATIENT SAYS YES PLANNED AND DID GET IT, THEN PROBE:

- ➡ How long were you going for radiation treatment?
- ➡ Were there times when it was difficult for you to keep your appointments? Why?
- ➡ Was it difficult getting your treatment covered under your insurance or any other type of payment plan?
- ➡ What hospital was your radiation scheduled at? Is this far from your home?

- ➡ Did you also see someone else that helped you with the side effects of the radiation? How did they help?

11. Was hormonal therapy planned as part of your treatment?

IF PATIENT SAYS NO THE HORMONAL WAS NOT PLANNED CONTINUE TO IMMUNOTHERAPY:

IF PATIENT SAYS IT WAS PLANNED BUT DID NOT GET IT DONE, PROBE:

- ➡ What happened that you did not have hormonal therapy?
- ➡ Did your physician or anyone from the hospital contact you regarding your decision not to have your hormonal therapy?
- ➡ Did you see someone else for your treatment?
- ➡ Is there anything that would have helped you get your hormonal therapy for your breast cancer?
- ➡ Was it difficult to get health coverage for this treatment?
- ➡ Were you afraid of how the hormonal therapy would affect your body?
- ➡ Did you need to care for your loved ones?

IF PATIENT SAYS YES IT WAS PLANNED AND DID GET IT DONE, PROBE:

- ➡ How long were/are you going for hormonal therapy?
- ➡ Did you have a hard time getting your treatment covered under your insurance or any other type of payment plan?
- ➡ Did you also see someone else that helped you with the side effects of hormonal therapy? Who?
- ➡ Did you take herbs or other things to help you with the side effects of the treatment? What were those?
- ➡ Did they test you to see if you were receptor positive?
- ➡ Did they explain the advantages and disadvantages of hormonal therapy?

12. Was Immunotherapy planned as part of your treatment?

IF PATIENT SAYS NO THE IMMUNOTHERAPY WAS NOT PLANNED CONTINUE TO SECTION IV:

IF PATIENT SAYS IT WAS PLANNED BUT DID NOT GET IT DONE, PROBE:

- ☛ What happened that you did not have the immunotherapy?
- ☛ What hospital was your immunotherapy scheduled at? Is this far from your home? How many miles?
- ☛ Did your physician or anyone from the hospital contact you regarding your decision not to have your immunotherapy?
- ☛ Did you see someone else for your treatment?
- ☛ Is there anything that would have helped you get your immunotherapy?
- ☛ Was it difficult getting health insurance coverage for this treatment?
- ☛ Were you afraid of how the immunotherapy would affect your body?
- ☛ Did you need to care for your loved ones?

IF PATIENT SAYS YES PLANNED AND DID GET IT DONE, PROBE:

- ☛ How long were you going for immunotherapy?
- ☛ Were there times when it was difficult for you to keep your appointments? Why?
- ☛ Was it difficult getting your treatment covered under your insurance or any other type of payment plan?
- ☛ What hospital was your immunotherapy scheduled? Is this far from your home?
- ☛ Did you also see someone else that helped with the side effects of your immunotherapy?
- ☛ Did anyone ask you to participate in a clinical trial?
- ☛ Did anyone explain the advantages and disadvantages of participating in one?

SECTION IV: Spirituality/Provider Perception

Now, let's talk about other things that may have been important during the time of your treatment.

13. Thinking back, during the time of your diagnosis and treatment for breast cancer, what kind of spiritual guidance was important to you?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ➡ Did you see a spiritual healer/curandera(o) or a medicine man for guidance?
- ➡ Did you see a minister/priest or a pastor for guidance?
- ➡ Did you participate in healing/cleansing ceremonies and/or prayer /attending church service/lighting candles/making a “promesa” at this time?
- ➡ Did you get something made or buy something for you, for spiritual protection to help you through this time?
- ➡ Can you tell me what those were?
- ➡ Were you allowed to keep these items with you while undergoing more tests?

14. I want you to think back on your experiences with the physicians, oncologists and other providers involved in your diagnosis and treatment for your breast cancer. Tell me what they said or did that made you think they “cared” or “didn’t care” about you during that time?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ➡ Did the doctor show concern for you?
- ➡ Did the doctor listen to you? Or spent time with you?
- ➡ Was the doctor patient with you and your family about what you wanted to do?
- ➡ Did the doctor call you or arrange for an appointment to explain the results?
- ➡ Did the doctor take the time needed explaining your diagnosis/treatment to you?
- ➡ Did the doctor involve your family?

15. I want you to think back on your experiences with the nursing staff involved in your diagnosis and treatment for breast cancer. Tell me what they said or did that made you think they “cared” or “didn’t care” about you during that time?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ➡ Did the nursing staff show concern for you?
- ➡ Did they listen to you? Or spent time with you?
- ➡ Did the nursing staff take time explaining your diagnosis/treatment to you?
- ➡ Did the nursing staff involve your family or comforting to them?

16. I want you to think back on your experiences with the clinics and hospitals where you visited for your diagnosis and treatment for your breast cancer. Tell me how did you feel about the facility during that time?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ➡ Was the clinic/hospital easy to get to?
- ➡ Did you or your family feel comfortable when visiting for your diagnostic/treatments?
- ➡ Did the facilities offer a comfortable place for your family to stay while you received treatments?
- ➡ Did you feel that the clinic/hospital was a place that would make you get well?

SECTION V: Quality of Life

17. How has your life been since your diagnosis and treatment for breast cancer?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ☛ Have you returned to work?
- ☛ Have you been able to care for your family?
- ☛ Has your energy returned or has it changed?
- ☛ Are you in any pain?
- ☛ Are you worried about a recurrence?
- ☛ Have you returned for more treatments related to your breast cancer?

18. How has your diagnosis of cancer changed you and your family?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ☛ How has it changed what you want out of life?
- ☛ Has your family been more informed about cancer and the importance of screening tests?

19. Thinking back on your experience with your diagnosis and treatment, is there anything that you would have done different?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ☛ Would you have gone somewhere else for your diagnostic/treatments?
- ☛ Would you have obtained more information?
- ☛ Would you have not had some of the treatments that you had?
- ☛ Would you have had a second opinion?
- ☛ Would you have asked about clinical trials?

The “Sharing of Our Experiences with Breast Cancer” Project Participant Contact Log

| | | | | |
|-----------------------|-----------|---------------|---------------|-----------------------|
| <u>PARTICIPANT ID</u> | 02 | <u>FAMILY</u> | <u>SOURCE</u> | <u>INTERVIEWER ID</u> |
|-----------------------|-----------|---------------|---------------|-----------------------|

M/C= mailed contact letter

I/P= in person contact

T/C= telephone contact

T/LB= telephoned/line busy

T/LMP= telephoned/left message w/person

T/LMM= telephoned/left message on machine

T/S= telephone screener completed

A/C= address changed

F/F= face to face interview completed

T/I= telephone interview completed

U/C= unable to complete (deceased, distressed, ineligible)

R= refused

LTF= lost to follow-up

**The “Sharing of Our Experiences with Breast Cancer”
(SOEBC) Project**

Case I.D: _____ **02** **PARTICIPANT ID** **FAMILY** **SOURCE** **INTERVIEWER ID**

Date of Interview: _____ / _____ / _____

Language (s) of Interview (please circle one):

English **Spanish** **Spanish & English** **Navajo** **Navajo & English**

Family Discussion Guide

SECTION III: PRE-DIAGNOSIS AND DIAGNOSIS

First, I would like you to think back before (loved one's name) breast cancer.
(Interviewer ask Q1).

1. Before you learned about (loved one's name) diagnosis, did you know that something had changed with her breast?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ☛ Can you tell me if you noticed or felt any changes with her breast?
- ☛ Can you tell me if she told you of any changes with her breast?
- ☛ Can you tell me if she spoke of symptoms?
- ☛ Can you tell me if she find out about it from a screening mammogram or a breast exam?

2. Tell me how you first learned about (loved one's name) breast cancer diagnosis?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ☛ Who told you about the diagnosis?
- ☛ When did you first learn about the diagnosis?
- ☛ Were you told before or after her biopsy or when treatment began?
- ☛ How did you feel learning of the diagnosis when you did?

3. Can you tell me what you felt when you first heard that (use loved one's name) had "cancer"?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ➡ How did you feel when you first heard that she was diagnosed with breast cancer?
- ➡ Why did you think she was diagnosed with the cancer?
- ➡ Did you feel she did something to bring on her cancer?
- ➡ Did you think that you could also get her cancer?
- ➡ Did other family members also feel this way?
- ➡ Do you think that she will get well?
- ➡ Do you think there are things we can do so that we don't get cancer?

4. Can you tell me what types of things helped you deal with her diagnosis?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ➡ Did you talk about the diagnosis with (use loved one's name)?
- ➡ Did you participate in healing/cleansing ceremonies and/or prayer attending church service/lighting candles/making a "promesa" with her or alone at this time?
- ➡ Did you talk to other relatives? Who?
- ➡ Did you talk to friends?
- ➡ Did you talk to someone for spiritual guidance?
- ➡ Did you get information on breast cancer?
- ➡ Did you talk to someone who knows about cancer? Who?
- ➡ Did you talk to someone in your community that you trust? who?

5. Can you tell me about what kind of help you gave her during that time?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ➡ Did you go with her to the appointments?
- ➡ Did you offer help with transportation or money to get her to the appointments?
- ➡ What other things helped her during this time? (making meals, household chores/taking care of children/grandchildren, sitting with her at the doctor's office, talking to her doctors)
- ➡ Who else in the family helped with these things?
- ➡ Do you think that you were able to help her enough?
- ➡ Did you feel she needed more help than what you had to offer? Like what?

6. Can you tell me how you felt about the help you gave her during this time?**INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:**

- ➡ Did you feel it was important for you to help her? Why?
- ➡ Did you feel burden because there was not enough time or money to help her?
- ➡ Did you feel you needed to be strong for her or the rest of the family?
- ➡ Did you feel your help was needed?
- ➡ Did you feel frustrated because it was hard for her talk to you?
- ➡ Did you feel that she would talk to you when she was ready?

7. How did you feel about the treatment planned for (use loved one's name)?**INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:**

- ➡ Did (use loved one's name) talk to you or other family members about the planned treatment?
- ➡ What did the rest of the family think of the treatment?
- ➡ Did you or other family members think (use loved one's name) she should get a second opinion?
- ➡ Were you worried about how (use loved one's name) would pay for her treatment?
- ➡ Were you worried about how (use loved one's name) would get to her treatments?
- ➡ Did you go with her for her treatments?
- ➡ What was it like for you and other family members after she had her treatments?
- ➡ Were there times when you found it hard to take her to the doctor/hospital for her treatments?

8. Were you or other family members given any information about the treatment planned during this time?**INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:**

- ➡ Did someone give you information about the treatment plan?
- ➡ Did you get information in your own language?
- ➡ Did you read something on the type of treatments planned?
- ➡ Did you talk to (use loved one's name) about her treatment?
- ➡ Did you talk to anyone in your community that you trusted about the treatment planned for (use loved one's name)?
- ➡ Were you told about cancer support groups?
- ➡ Did you feel a need to join a support group?

9. Was surgery planned as part of her treatment?**IF FAMILY MEMBER HAS SAYS IT WAS PLANNED BUT DID NOT GET IT DONE,****PROBE:**

- ☛ What happened that she did not have the surgery as planned?
- ☛ Did she decide to go back and have it?
- ☛ How did you feel about her not having the surgery?
- ☛ Did you try to talk her into having her surgery?
- ☛ Did you try to get her to talk to someone else about her surgery? Who?
- ☛ Did you feel she should see someone else for her surgery? Who?
- ☛ Do you think there was something that could have helped her get her surgery for her breast cancer? What?

IF FAMILY MEMBER SAYS THE SURGERY WAS NOT PLANNED OR NO KNOWLEDGE OF IT CONTINUE TO CHEMOTHERAPY:**IF FAMILY MEMBER SAYS YES, PT HAD SURGERY PROBE:**

- ☛ How did you feel after her surgery?
- ☛ Did she need help with (errands, children etc.) while she was in the hospital?
Did she get help?
- ☛ Were you able or allowed to stay in the hospital with her?
- ☛ Did you visit her while she was in the hospital?

10. Was chemotherapy planned as part of her treatment?**IF FAMILY MEMBER SAYS THE CHEMOTHERAPY WAS NOT PLANNED OR NO KNOWLEDGE OF IT CONTINUE TO RADIATION:****IF FAMILY MEMBER HAS SAYS IT WAS PLANNED BUT DID NOT GET IT DONE,****PROBE:**

- ☛ What happened that she did not have the chemotherapy?
- ☛ Did she see someone else for her treatment? If Yes: Who?
- ☛ Is there anything that would have helped her get her chemotherapy for her breast cancer?
- ☛ Were you worried of how the treatment would affect her?

IF FAMILY MEMBER SAYS YES PLANNED AND DID GET IT, THEN PROBE:

- ☛ How did you feel about her chemotherapy treatments?
- ☛ Did she need help with (errands, children etc.) while undergoing her treatments?
Did she get help?
- ☛ How was she physically? Did you need help in taking care of her during this time?

11. Was radiation planned as part of her treatment?

IF FAMILY MEMBER SAYS RADIATION WAS NOT PLANNED OR NO KNOWLEDGE OF IT CONTINUE TO HORMONAL:

**IF FAMILY MEMBER SAYS IT WAS PLANNED BUT DID NOT GET IT DONE,
PROBE:**

- ☛ What happened that she did not have the radiation?
- ☛ Did she see someone else for her treatment? If Yes: who?
- ☛ Is there anything that would have helped her get her radiation for her breast cancer?
- ☛ Were you worried about how the radiation would affect her body?

IF FAMILY SAYS YES PLANNED AND DID GET IT, THEN PROBE:

- ☛ How did you feel about her radiation treatments?
- ☛ Did she need help with (errands, children etc.) while undergoing her treatments?
Did she get help?
- ☛ How was she physically? Did you need help in taking care of her during this time?

12. Was hormonal therapy planned as part of her treatment?

IF FAMILY MEMBER SAYS HORMONAL THERAPY WAS NOT PLANNED OR NO KNOWLEDGE OF IT GO ON TO SECTION IV.

**IF FAMILY MEMBER SAYS IT WAS PLANNED BUT DID NOT GET IT DONE,
PROBE:**

- ☛ What happened that she did not have hormonal therapy?
- ☛ Did she see someone else for her treatment? If Yes: Who?
- ☛ Is there anything that would have helped her get her treatment?
- ☛ Were you worried about how the hormonal therapy would affect her body?

IF FAMILY SAYS YES IT WAS PLANNED AND DID GET IT DONE, THEN PROBE:

- How did you feel about her hormonal treatment?
- Did she need help with (errands, children etc.) while undergoing her treatments?
Did she get help?
- How was she physically? Did you need help in taking care of her during this time?

13. Were there any other treatments planned for (use loved one's name)?

SECTION IV: SPIRITUALITY/PROVIDER PERCEPTIONS

14. Thinking back, during the time of (loved one's name) diagnosis and treatment for breast cancer, what kind of spiritual guidance was important to you or your family at that time?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ➡ Did you or other family members participate in healing/cleansing ceremonies and/or prayer/attending church service/ lighting candles/making a “promesa” at this time?
- ➡ Did you or other family members get something made or bought something for spiritual protection to help you through this time? Can you tell me what those were?

15. I want you to think back on your experiences with the physicians, oncologists and other providers involved in (loved one's name) diagnosis and treatment for breast cancer. Tell me what they said or did that made you think they “cared” or “didn’t care” about you and your family during that time?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ➡ Did the doctor show concern for you and your family?
- ➡ Did the doctor listen to you? Or spent time explaining or answering your questions?
- ➡ Was the doctor patient with you and your family about what you wanted to do?
- ➡ Did the doctor call you or arrange for an appointment to explain the results?
- ➡ Did the doctor take the time needed explaining the diagnosis/treatment to you?
- ➡ Did you feel the doctor involved you and your family?

16. I want you to think back on your experiences with the nursing staff involved in (loved one's name) diagnosis and treatment for breast cancer. Tell me what they said or did that made you think they “cared” or “didn’t care” about you and your family during that time?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ➡ Did the nursing staff show concern for you and your family?
- ➡ Did they listen to you? Or spent time with you?
- ➡ Did the nursing staff take time explaining your diagnosis/treatment to you and other family members?

SECTION V: QUALITY OF LIFE

18. Thinking back on your experiences with (loved one's name) diagnosis and treatment, is there anything that you would have done different?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ➡ Would you have gone somewhere else for her diagnostic/treatments?
- ➡ Would you have obtained more information?
- ➡ Would you have suggested not to have the treatments she had?
- ➡ Would you have suggested a second opinion?
- ➡ Would you have asked about clinical trials?

19. Tell me how (loved one's name) life been since her diagnosis and treatment for breast cancer?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ➡ Has she been able to return to work or do her regular household chores?
- ➡ Has she been able to care for the family?
- ➡ Has her energy level returned or has it changed?
- ➡ Has she returned for more treatments related to her breast cancer?

20. Tell me about your life since (loved one's name) diagnosis and treatment for breast cancer?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ➡ Have you been able to return to work or do your household chores?
- ➡ Have you been able to care for your own family?
- ➡ Have you needed more financial help since her diagnosis with cancer?
- ➡ Have you needed more emotional support since her diagnosis with cancer?

21. How has (loved one's name) diagnosis of cancer changed you or your family?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ➡ How has it changed what you want out of life?
- ➡ Has your family been more informed about cancer and the importance of screening tests?
- ➡ Have you and your family grown closer?

17. I want you to think back on your experiences with the clinics and hospitals where loved one's name and you visited for diagnosis and treatment for breast cancer. Tell me how did you and your family feel about the facility during that time?

INTERVIEWER: PROBE USING THE FOLLOWING QUESTIONS IF NO RESPONSE:

- ☛ Was the clinic/hospital easy to get to?
- ☛ Did you or other family members feel comfortable when visiting for her diagnostic/treatment visits?
- ☛ Did the facility (s) offer a comfortable place for you and other family members to stay while your loved one's name received treatments?
- ☛ Did you feel that the clinic/hospital was a place that would make loved one's name get well?